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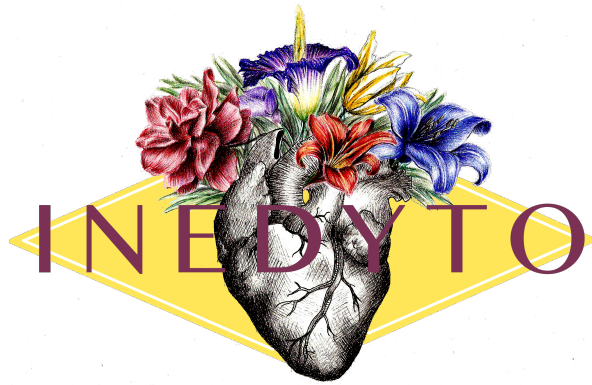
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The Role of the Family in Deceased Organ Procurement

Alberto Molina Pérez

FiloLab, University of Granada, Spain

Consent systems & role of the family

Review

Transplantation 2019



Role of the Family in Deceased Organ Procurement: A Guide for Clinicians and Policymakers

Janet Delgado, PhD,^{1,2,3} Alberto Molina-Pérez,^{3,4} David Shaw,^{3,5,6} and David Rodríguez-Arias^{3,4}

The basics

The deceased person preferences

- 1) Consent (cornerstone of organ donation ethics?)
- 2) Refusal (WHO's first principle)
- 3) Election of a surrogate
- 4) Say nothing, do nothing

Three models:

Opt-in

Opt-out

Mandatory choice

Two defaults:

To harvest organs

To do nothing

Definitions

- **Organ procurement**
- **Organ donation**
- **Consent v. authorisation**
- **Refusal v. opposition**
- **Family**

Relatives intervention in the system

1) Obtaining and recording the deceased's wishes

- a) Family can *inform* about the deceased's preferences
- b) Family can *update* the deceased's preferences

2) Overruling the default policy

- a) Family can *authorize* procurement
- b) Family can *oppose* procurement

3) Overruling the deceased's wishes

- a) Family can *overrule a consent*
- b) Family can *overrule a refusal*

Deceased's wishes	Model of consent	Role of the family			
		No role (L0)	Witness (L1)	Surrogate (L2)	Full decisional authority (L3)
Unknown	Opt-out	—	Can <i>inform</i> about the deceased's wishes	Can <i>oppose</i> organ procurement*	Can <i>oppose</i> organ procurement*
	Opt-in	—	Can <i>inform</i> about the deceased's wishes	Can <i>authorize</i> organ procurement*	Can <i>authorize</i> organ procurement*
Consent	Opt-in, Opt-out	—	Can <i>update</i> the deceased's wishes	Can <i>update</i> the deceased's wishes	Can <i>overrule</i> consent
Refusal	Opt-in, Opt-out	—	Can <i>update</i> the deceased's wishes	Can <i>update</i> the deceased's wishes	Can <i>overrule</i> refusal**

Laws v. clinical practice in the world

Level	0	1	2	3
Role of the family	No role	Witness	Surrogate	Full decisional authority
Law	Argentina Austria Uruguay	Chile France Singapore Spain	Belgium Canada Germany Netherlands* Sweden UK** USA	India Japan
Practice			Belgium Germany Singapore Sweden	Austria Canada Chile India Japan Netherlands Norway Portugal Spain UK USA***

Model of consent	Role of the family				Source	
	L0 No role	L1 Witness	L2 Surrogate	L3 Full decisional capacity		
opt-out	law	AR, AT, PT ^a , UY	CL, ES, FR, SG, WA ^b	BE, CH ^c , SE, NO ^d	JP	Delgado 2019
	practice			BE, FR ^e , SG	AT, CL, ES, JP, NO, PT, WA ^b	
	unspec.			BE, FI, SG, SE	AM, AT, BY, CL, CO, CR, CZ, EC, ES, FR, HR, IT, LU, NO, PL, PY, RU, SI, SK, TN, TR	Rosenblum 2012
	unspec.	AT, CZ, LU		GR, PT, SK	BE, ES, FI, FR, HR, HU, IT, NO, PO, SE, SI	Bilgel 2012
opt-in	law			CA, DE, NL ^f , UK ^g	IN	Delgado 2019
	practice			DE	CA, EE, IN, NL ^f , UK ^g	
	unspec.			NL, RO, UK, USA	AU, BR, CA, CH, CU, DE, DK, EE, IE, IL, IN, IS, JP, KR, KW, LT, MT, MX, MY, NZ, PH, SA, TH, VE, ZA	Rosenblum 2012
	unspec.	CA			AU, CH, DE, DK, IE, IL, NL, NZ, UK, USA	Bilgel 2012